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**The Role of Families in HIV Prevention, Treatment, Care and
Support
Kaiser Family Foundation
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JOHN MILLER: Thank you for coming to this, probably one of the worst timed sessions in the conference, but for a topic we hold very dear to our hearts. My name is John Miller. I'm with the Coalition on Children Affected by AIDS. This is Stefan Germann from World Vision International and also on our steering committee and will be co-chairing this session on the role of families in HIV Prevention, Treatment, Care and Support.

A year ago, the Joint Learning Initiative on Children and AIDS presented its findings, and we saw really very compelling evidence that families were backstopped by communities and shouldering the majority of the care and financial burden for children affected by AIDS.

The recommendations and evidence from the Joint Learning Initiative's findings pointed very clearly to social protection agenda, which was already gaining a lot of evidence and which we were pleased to see gain some momentum then. But one of the other findings of the Joint Learning Initiative prompted some initiative on the behalf of the Coalition of Children Affected by AIDS to promote and gather evidence and give prominence to some work that had been going on for some time, and that was that service provision was not adequately supporting families.

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We organized a series of meetings on family centered services last year and commissioned a series of academic papers on the subject, some of which have been published in a special issue of the *Journal of the International AIDS Society*, and there are copies at the back, if you wish to get them.

What do we mean when we say family centered services? These are services that recognize that we do not live in the world as individuals, but rather with people whom we love and consider family, whether they're biological families or chosen families. In other words, however we define them.

The evidence is crystallizing. These models do have a greater chance of producing better outcomes in both adults and children. But, something else became clear as part of our meetings, that these models often aren't friendly to especially marginalized communities, drug users, men who have sex with men, sex workers, migrant and refugee communities, prisoners.

These presentations in this session today will touch on various aspects of this topic. So I'm going to turn it over to my co-chair to introduce you to the first speaker.

STEFAN GERMANN: It's my pleasure to introduce our first speaker, Marie Adamyan. She's working with World Vision in eastern Europe and central Asia. She's a public health professional and has many years of experience in health and HIV within that region and specifically related to children in at-

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risk situations and marginalized population groups. Marie, go ahead. Thank you.

MARIE ADAMYAN: Thank you for coming. I will be sharing about children of especially marginalized group, and a little bit of our experience in the field with family centered approaches to help prevention of HIV. I will share a little bit about vulnerabilities and risks and challenges that exacerbate those vulnerabilities and risks for children and youth in the region. I will share four examples from four different projects in the region. Also, some key recommendations and learnings that we had from those programs for importance of the family centered approaches when it comes to HIV prevention and prevention of risks and vulnerabilities for children and youth.

Well, it is not news that this region is unique in terms of the politically and social economic transition since the crash of the Soviet Union. For those many years, we are still struggling.

We have those rapid social changes that are still ongoing. The war and arm conflicts are here and there at Hoakely [misspelled?] happening, and political armistice is the norm. There is a huge gap in reaching the poor in the region. Of course, the environment is not helping HIV prevention either. So basically, 20-percent of children, according to UNICEF data, live with single parents and with very, very easy

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access to drugs and alcohol. It increases their risk and vulnerability, of course.

The third of HIV positive people are women and girls. Then 58-percent of women and girls reported that they've never heard about HIV and AIDS. So you can imagine the risks and vulnerabilities for those children, women and girls. So, the innovative employment opportunities are there, as well. Labor migrants, it's a normal job to be a labor migrant, especially in caucuses in central Asia. People leave, for breadwinning purposes, to Russia and Ukraine mostly, which are the high prevalence countries in the region, Turkey as well. So, this is the most popular job now for central Asia and caucuses.

But at the same time, they leave their children behind. In many cases, by themselves or with grandparents. The most popular job opportunities for children and youth is also sex work and drug dealing. Those are unspoken issues, and I do want to emphasize that these issues are unspoken, hidden. There is not much data about this, but we see this through our programming, and we know because we live in this region.

Traditionally, family is the primary provider of protection, care and support influencing child social development. That's the norm. It's still there, but because of the confused hierarchy of values and norms and social identity of parents and children, a lot of change has happened. Risks

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are not limited only to HIV, but there are many, many risks that I already mentioned that exacerbate the risk of HIV.

It is more about vulnerability than orphanhood in this region, as opposed to Africa, for example, when we're speaking about OVC. The gay, those vulnerabilities are not spoken about. The huge army of street children, for example, exists in this region, but no one does real, targeted, tailored programs for HIV prevention for them.

There is lack of focus for vulnerability and risk reduction in general, but at the same time, lack of focus on family centered approaches. So those weakened family ties, diverse hierarchy of traditional norms and system replacement, basically family and friends are replaced with drugs and alcohol in most cases, this is the environment that our children and youth live in.

I want to share with you the enabling environment framework that World Vision uses for its programming because this is the center of our decision why family centered approaches matter. This is based on an ecological model that most of you are familiar with, I guess. Individual, in this case child and youth, are the center. Then, their immediate environment is the family or institution where they're living or teachers in this institution or their immediate peers. Then, we, as World Vision, target spiritual support as well. So faith

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leaders and congregation members would be the next circle. Then, the bigger circle is the social environment where we have AIDS centers, for example, that we work with, other NGOs who we partner with, larger community leaders and opinion makers. But most importantly, we target the immediate environment. I want to say that we didn't do it for many programs, but then we learned, through our experience, that that should be the case.

So the first example I want to share is from Uzbekistan, and this is one of our long-term programs that we had. It was closed recently because of the political reasons. We were targeting injecting drug users and sex workers in one city, the capital city of Tashkent, to trust points and it was comprehensive programs. So we targeted all those layers. But, we failed to focus on children and families because it was really a harm reduction program focused on sex workers and drug users. We learned through our program that we need to target families. We need to target those children who live in those families and wives and dependants of drug users and sex workers. So we paralleled another program. We learned that because we started speaking to children and the dependants. So, in that particular program, we added the dependant counseling element. We did it in five out of ten trust points. It proved to increase the attendance by drug users. It proved to improve their own access to services and avoid self-stigma.

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The next program I want to share about is our program in caucuses. We're doing three countries, Armenia, Georgia, Azerbishan. We are targeting labor migrants, who I mentioned, that most leave their children behind by themselves or with mothers or grandparents. So we are targeting the families of. I remember our donors questioned that. They asked, you're not targeting migrants really, you're targeting their families in the first place. Yes, because we learned through our other programming that targeting family will help migrants. The targeted promotion VCT used by children for their fathers works. Prevention messages that the family gives to the labor migrants who is coming back home for a few months work.

The other program that we had is in Russia. So we targeted vulnerable children and youth. You may know that in Russia, the families are like split into two types. It is normal families, which means parents are normal. There are no drug users or alcohol, excessive alcohol consumers. Or unadapted families, which is the alcohol consumers' families or the drug users' families, or difficult families in general. So we targeted children who were in boarding schools from difficult families. Then in another program, we targeted children who were living in normal families, but they were, themselves, involved in alcohol abuse, drug use or crimes. So reinforcing family importance for the normal families helped

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them be back more with families and less time in the street. While we didn't focus on family at all with children in abnormal families, which were in boarding schools. We targeted institution teachers. We targeted faith leaders who worked with them. But this approach helped them reestablish the value system as they say during the evaluation and prioritize their family more. So even without being intentional about family but focusing on value promotion in general, these children mentioned during the interviews for evaluation that that was important for them, and they reinvestigated the importance of the family in general for them. Meaning that they spent less time in the streets, basically, or with risky behaviors.

Bosnia and Herzegovina, we worked with Roma, women and youth, women and girls particularly, but mostly they're under 24 years of age. Roma is the most marginalized population group in Europe, but their issues are unspoken. So many children are involved in child labor and risky behaviors. Alcohol use and drug use is kind of normal. So in our programming, we really had family centered approach for HIV prevention. That increased access to services. They don't know the rights for being eligible for services. This program particularly helped for families, especially children and youth accessing the rights for health care and for prevention.

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What we're learning from our programs, very briefly, is, I already mentioned and I just want to summarize, that it goes both ways. It's not that we focus on family centered approaches to help those in families, but it helps marginalized groups themselves to less self-stigmatize and have easy access and better access to services. Like, for example, the police violence is hindering that access. Exactly that way, family centered approach helps for better access and better prevention.

Then it also helped less attraction to streets for children and youth and less time for risky behaviors. Most importantly, it created an enabling environment for children and youth to freely share opinions and access their rights and know their rights.

So the recommendations are to intentionally plan family centered approach in your program designs. As I mentioned, in some of our programs, we didn't do that at first. Then we learned through our experience that this is important. So, building family centered approaches for children and youth, particularly, and dependents into program design will help implement it.

So those elements of the program should not come by the way at Hoakley. Then, tailor interventions for parents and caregivers for vulnerable children. Specifically, we kind of

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take it for granted that parents and children will be doing it, but it's not happening. So if we are intentional for helping them know how to help their children, that works. Of course, keep children and their rights in mind, even when they are invisible because these children, especially in this region, they're mostly invisible. They are not seen. We don't speak much about them. So vulnerable children in eastern Europe and central Asia need protection and rights based family approaches. Family centered approaches need to be part of the program design. Thank you very much. [Applause]

STEFAN GERMANN: Thank you Marine. Our next speaker is quite easy for me to introduce her as we have the privilege of having the plenary speaker from this morning, Elaine Abrams. She's a professor in pediatrics at Columbia University and part of the Mailman School of Public Health. We had this morning a fantastic presentation from her on vertical transmission, and now we will have an ability to listen to the role on family and can probably go into a bit more details on the presentation this morning. Thank you for this morning's presentation.

ELAINE ABRAMS: Well, thank you so much. As a pediatrician, I have some favorite children's stories. One of my favorites is *Martha the Dog*. Martha's a dog who eats a bowl of noodles in the shape of alphabets, and she starts talking. Every day, they give her more alphabets, and she keeps talking.

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This is my sixth presentation in as many days, so I'm feeling a little bit like Martha the Dog in hoping somebody will take my alphabets away from me, so I can be quiet.

So I'm going to try to, very briefly, talk with you about the role of families in the prevention of vertical transmission, and very specifically share with you the experiences from the MTCT Plus Initiative, as a family focus program for women, children and their families. Let's see if I can get this right this time. So, first I'm assuming everyone has the take home messages about when vertical transmission occurs and how and the risk factors. But I thought I'd spend a moment just talking about the spectrum of care and what it is that goes into actually trying to prevent transmission, and the kind of services that need to be provided.

I'm sorry that this is not projecting as well as it could, but I think what it does, it gives you a sense that prevention of mother to child transmission or vertical transmission is a long-term intervention for the woman and should really start at pre-conception, having a woman and family make a decision about more children. It requires testing, both for HIV and CD4 during pregnancy, a safe delivery, and then it doesn't end there. It really continues until the child is well into the second year in life, and to the mother is effectively engaged in HIV care for her own

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health. It should not just be about the baby, but more specifically, about the mother.

So effective PMTCT includes a series of both biomedical and psychosocial interventions that are administered throughout the reproductive life of a woman living with HIV. Really, you have to keep in mind that, certainly in high prevalence settings, that women have multiple pregnancies, so this is often a recurring pattern of care that'll happen throughout a woman's reproductive life.

On the other end of the spectrum is the care for the infant. As I stated, it can last well into the second year of life, particularly if the child is breastfeeding. It starts at birth with antiretroviral prophylaxis. Now with the new guidelines, the baby or mom will be receiving prophylaxis throughout the first year of life. There are multiple well-child and HIV specific interventions that need to occur across this period of time. If you put it together, you actually have quite a lot to do as a service provider to ultimately result in a happy, healthy family.

So let's look at the evidence around PMTCT, or vertical transmission and family centered care. By definition, it is a family focus or family centered intervention because it entails the mother and the child, this dyad. It also provides an unparalleled opportunity to engage other family members in HIV,

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as well as other health and social services. So it's an opportunity to test a husband or partner, other children in the family and other extended family or household members, and to provide HIV testing, prevention and care. It's a fabulous platform for all of these things. It's also a platform for other health services, particularly things like TB or early infant interventions. Ultimately, as I showed this morning, effective PMTCT prevents orphanhood because it not only should prevent infection in babies, but should effectively keep mothers and fathers healthy.

There's also evidence that family involvement can enhance prevention of vertical transmission. Partner testing in vertical transmission programs has been associated with greater use of prophylaxis, higher acceptance of post-test counseling and increased communication between partners about HIV and sexual risks. If you use PMT services as an entry point into care, you can also retain adults, particularly the pregnant women and child and have better adherence. Family focused home-based testing has been very effective and can overall improve the outcomes for both HIV positive and negative family members. Disclosure status within the household has been associated with better pediatric outcomes.

So I'll tell you a little bit about the MTCT Plus Initiative. This is an multicountry HIV care and treatment

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program that use PMTCT as an entry point for pregnant women and postpartum women into comprehensive HIV care and treatment. It was also an entry point to identify other family members who were in need of HIV services. It reframed PMTCT in the context of the reproductive lives of women living with HIV, recognizing that pregnancy was a normal and expected aspect of a woman's life and in aim to support and maximize the health outcomes of the woman, the child and the family. It became a model for family focused care.

So there are many factors that shaped the development of the MTCT Plus model, recognizing HIV as a multigenerational family disease where multiple family members across the generations could be infected, that all family members are affected by HIV once any member has the infection. That most HIV care actually occurs outside the facility, but rather in households and among families. That women and children, in particular, have multiple needs; they're not just medical, but may impact adherence to their medical services. Families can be an important source of support for treatment, and that community and cultural factors impact on adherence and retentions. So the MPlus approach to care and treatment provided comprehensive primary care, which included antiretroviral therapy, which is somewhat different for many of the antiretroviral therapy programs that specifically enroll

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individuals who need treatment. It was family centered, and at the time that it started in the early-2000s was really revolutionary by including children, paid attention to a wide range of factors, provided care by multidisciplinary team, including social workers, nurses and physicians, and involved persons living with HIV.

These are all the countries where MTCT Plus sites, nine countries in Africa as well as in Thailand. Women attending antenatal clinics would be tested for HIV, enrolled into PMTCT programs and then offered enrollment into MTCT Plus where they got a package of care. They were invited to enroll HIV infected partners and children. Over the course of the initiatives, there were 16,000 individuals, more than 16,000 individuals enrolled, about 60-percent adults and 6,000 children. For adults, about 40-percent started on treatment and about 40-percent of women were enrolled during pregnancy.

Of particular interest, in the family focus model of the enrollment of partners into HIV services using PMTCT as an entry point. As you can see here, I notice this graph only goes as high as 35-percent, that during enrollment in the early 2003 to 2005, there was great variation by country where sites were located in the ability to enroll partners. Some countries did relatively well, while others only had modest numbers of partners enrolled. This is very dependent upon how individual

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programs were established, as well as things like migration within the community, whether men worked in distant places and what other services were available.

In the MTCT Plus Initiative, the majority of women received multidrug regimens for PMTCT. When women initiated HAART during pregnancy, they had a robust, actually extremely robust, response with other 450 CD4 cell response after 30 months. Retention and care and treatment was unusually high for both women and men compared with reports from many ART programs. Women who started treatment were almost twice as likely to have a second child in the initiative than women who were just followed in care.

I'm hoping you can hear this [video played]. I'm not sure you could hear that any better than I could. That was Dr. Dio at our Malaga MTCT Plus site who was expressing the virtues of family focus care. So you'll have to take my word for it.

If you're in the hallway where the session rooms are and where those wonderful sculptures are all the way at the end, there actually is a television that plays a series of films from MTCT Plus all reflecting on the family focus model of care. I urge those of you who are around tomorrow to go see them. They're quite beautiful.

So in conclusion, HIV infection affects the health and the wellbeing of families, as well as individuals. Most

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prevention care and treatment programs have been established to address the needs of the individual, very often neglecting the family. Prevention of vertical transmission services offer an unequaled opportunity to address the comprehensive health needs of the mother and the child, to engage partners, children, other family members and to enhance PMTCT outcomes by engaging family members. To date, there have been very few models of family focus PMTCT that have been either trialed or evaluated. But hopefully with renewed global attention and commitment to the health needs of women and children we'll have an opportunity to focus on families as a means to keep families healthy and children free of HIV infection. Thank you.

[Applause]

JOHN MILLER: Thank you very much Professor Abrams. Our next speaker is Maurice Tomlinson. Maurice Tomlinson's an attorney at law in Jamaica and has been involved in HIV/AIDS and lesbian/gay/bisexual/transgender and intersex activism in Jamaica for over 12 years.

He is company secretary and legal adviser to Jamaica AIDS Support for Life as well as legal counsel for Jamaica Forum for Lesbians, All-sexuals and Gays. He was recently appointed to the International Lesbian and Gay Association Latin America and the Caribbean as a regional secretary for Gays Caribbean.

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Maurice is also a father to one biological child and two foster children, one of whom is HIV positive. We had the pleasure of having him speak at our meeting in February on especially marginalized groups and family-centered support. Please join me in welcoming him. [Applause]

MAURICE TOMLINSON: Thank you John. And thank you all for coming out. As John said, I know it's a very difficult time. But this is a very important topic. I'm going to just take you quickly through the outline of what I'm going to do today.

I'm going to talk about the definition of what family-based care is to me and to the groups represented here, and what are the relevant legal issues that are thrown off from that definition. Some international commitments in relation to MSM and their role and their participation in family-based care. The state of international and criminal MSM criminalization; just a quick overview, because I'm sure you've all heard this before. The impact of MSM criminalization in relation to family-based care from the Indian experience, that we got some excellent work done by Doctor Sunil Solomon. And impact on OVCs, orphans and vulnerable children, of MSM criminalization, some examples of stories that we have heard.

So, what is the definition of family-based care that we are working with? It's a focus on the family as opposed to the

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physician. Family are the central deliverers of care. And this care goes beyond medication. It involves adherence, the social aspect, emotional support, attendance to financial, physical, and other needs, and therefore implicates a more holistic approach to care.

And the reasons for family-based care are obvious in that the health care provider can not provide all the care, all the time. They are responsible for providing care at the point of care, which is usually the hospital or clinic. So family-based care is critical to ensuring an effective response to the HIV epidemic.

What are the legal issues that arise in relation to family-based care and MSM? Well, firstly, disclosure. How much, when is it necessary, what is the type of disclosure that should be made.

And the family types that are recognized for family-based care in relation to MSM. We have situations of opposite-sex married MSM, civil union or same-sex married MSM and children. Those are just some, I'm sure there are many other legal issues in relation to family types. But I have to be brief.

So in relation to the family, the concept that is traditionally accepted in discourse about family is what you see here: mother, father – you know, the 2.5. However, the

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international commitments regarding MSM and family-based care don't make any such presumptions, actually. The international commitments as are found in the treaties that are listed there provide for privacy and non-interference with family and home of everyone, right to marry and to form a family, of everyone, and the right to the highest attainable standard of health, for everyone.

So there is no distinction in any of the international treaties at least that I have found which predicate family, home, privacy, etcetera on heterosexual contexts. It doesn't exist.

One of these particular international treaties, the one that most persons will cite in relation to civil and political rights, family rights, and privacy, is the International Covenant on Political and Civil Rights. There is almost universal acceptance of this treaty. And therefore its provisions in relation to privacy rights, family rights etcetera have reached the standard of almost customary international law.

Yet the picture in relation to laws regarding same sex sexuality is a little different. As you must have heard before, there are about 80 countries that still have criminalization to one extent or the other. Some have even the death penalty.

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So what does this mean for family-based care? Well, I'd like to point to the Caribbean that I know a little bit about. The regime in relation to criminalization of same sex intimacy there is from life imprisonment in Guyana and Barbados to 10 years in Jamaica, Belize, Grenada and some other countries. In Trinidad and Tobago for example, it is criminal to enter the country if you are an MSM.

The constitution of Jamaica, just like many other Caribbean territories, has a provision in relation privacy which coincidentally also covers family life. And you'll see the relevance of all of this to family-based care shortly. So it says, whereas everyone in Jamaica is entitled fundamental rights and freedoms, including respect for his private and family life, which would seem to be very clear.

The constitutions have what is called a savings law clause. Which means that any law which existed prior to our independence is saved, no matter how draconian and backward and archaic such law is. The result is that the 1864 Offenses against the Persons Act which we inherited from Britain, which speaks to unnatural offenses and outrages on decency – these laws are saved.

Therefore even though they directly impact on the right to privacy of MSM, they cannot be challenged in a domestic court. Parliament is the only agent that can change such laws,

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and of course that has serious political implications in a context where societies are still very conservative.

In relation to MSM and family types, the general situation is that same sex unions are rarely granted legal status. Definitely in the Caribbean it is not recognized. We see movement happening around the world, in Latin America, but definitely not in the Caribbean.

There is a prohibition on same sex union in a case called Corbett and Corbett which can only be removed by legislative action, which seems quite unlikely. This prohibition has negative implications on provision of family benefits, health care attendance, etcetera.

We have a situation in some of our Indo-Caribbean populations, especially where heterosexual marriages are entered into for family, financial, social etcetera reasons often with tragic results. That is why I thought it was important to look at the example of India and the implications of criminalization for family-based care in India. Because it resonates very well with what happens in the Caribbean.

In India, in a study presented by Dr. Sunil Solomon, they found that there was a great deal of stigma and discrimination as a major concern, which is why there was non-disclosure about HIV status. The fear of acceptance by the family was a major barrier to disclosure.

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There was marriage due to parental pressure, and the criminalization meant that if they were discovered, they would have faced prosecution, so they would keep their condition secret, with the result of course that not only did they not receive the treatment they needed but they also infected their family members. And we see the statistics: only two percent disclosed to wives, six to family members, 15 to healthcare professionals.

Now, I'm rocketing along. In relation to children and MSM, in the Convention on the Rights of the Child we see where the states parties are required to protect the child and his family, his parents, from discrimination, regardless of their status or any other criteria.

There's the catch-all phrase that the best interests of the child shall be the primary consideration. However, this has been interpreted in certain contexts, certainly in the Jamaican context, to mean that any situation which puts the child in moral danger or exposes the child to substantial risk can provide an opportunity for that child to be taken out of the situation.

Now normally that's a commendable thing. However, when you have laws such as the Offense against the Persons Act, which criminalized same sex activity, that can be used and has been used to separate families and to prevent children from

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remaining in their family situations where they can receive care, because one partner, the surviving parent, might be an MSM. In our context, the penalty for not reporting what is considered abuse, which is exposing a child to moral danger or substantial risk is a fine of \$500,000 or to imprisonment not exceeding six months, or both.

The finding in relation to MSM and exposure to moral danger is not substantiated by findings of longitudinal studies of children in same-sex households. The American Psychology Association has found, as far back as 2005, that children raised in same-sex households are as well-adjusted as children in heterosexual households. And of course there are ongoing studies to show that they are performing sometimes even better.

But in the Karen Atala case, which was out of Chile and has importance for us in the Americas, in the Caribbean, because we share the Inter-American Commission, a lesbian judge living with her partner was denied custody of her three children because of perceived moral danger. The Inter-American Commission found on April 7, 2010, the same day that we held our Walk for Tolerance in Jamaica, that discrimination against the parent in a child custody dispute because of her or his sexual orientation violates the American Convention on Human Rights.

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However in Jamaica, the policy remains that the mother is usually best, no single male will be allowed to foster or adopt a female child, and from my personal experience, a single male adoption of a male child is always frowned upon, even if that child has no other means of care, even if that child is an OVC.

I'm just going to quickly share a story – not my personal story which you can hear after, which is not being taped – of a situation where a Jamaican MSM sought to provide care, and the challenges he faced to provide care for an OVC who would otherwise have been left in an institution.

So, he heard about an orphan positive child. He took him in an unofficial fostering arrangement, which is quite popular. After three years he decided to adopt the child, to give the child a sense of belonging, access to health care and other benefits.

He applied to adopt this child through the Adoption Board, which did several home visits, interviews, etcetera. There was clear evidence that the child improved in all the markers from AIDS characteristics. He was however met with resistance from the conservative female adoption officer and he had to spend a tremendous amount of money to employ a senior counsel, who eventually became the chairman of the Adoption

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Board after this case was won. The judge commented on the obstructive nature of the adoption official.

The adoption was finally approved after three years. But the time and the expense that this person undertook to get this child, not many persons would have been willing to undertake that.

The fact is that in Jamaica, within the Kingston metropolitan region alone, there are eight infected children in children's homes receiving substandard care. Adoption of these children is a viable option to addressing this issue, and many MSM have expressed the desire to do so, but there are policy implications and impediments.

So, in summary: criminalization of same sex intimacy undermines family-based care by fostering non-disclosure. That's not rocket-science. Non-recognition of same-sex union limits family-based care by denying family benefits. And finally, OVCs, orphans and vulnerable children's access to potential parents is denied due to our homophobic childcare policy. Thank you. [Applause]

JOHN MILLER: Thank you Mr. Tomlinson for a very compelling presentation about the barriers to this model from your perspective. Our last speaker, who's a discussant in this session is Laxmi Narayan Tripathi. Miss Tripathi is a hijra social

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activist working in the field of HIV and AIDS for the past 10 years.

[Applause]

She's the founder of the CBO Astitva, for the support and development of sexual minorities and a co-founder of the Asia-Pacific Network of Transgenders. She was the first transgender person to represent Asia-Pacific in the UN Civil Society Task Force. She's also an accomplished Indian dancer, an actress, and the first transgender entrepreneur I believe in India. Please welcome Miss Tripathi. [Applause]

Laxmi Narayan Tripathi: Hi. Good evening everybody. I'm going to talk about sexual minorities. Now my counterpart spoke about MSM, generally. The issue of sexual minority is not as far as MSM even in the transgender community and the communities of which even I be present, the hijra, the oldest and the ethnic transgender group.

In India, as far as MSM is concerned, there is lots and lots of work done. There are CBOs, NGOs, and the NACO's rule, and there's enough of money. But there are some rules where community center where even we commonly with MSM face a lot of problems.

But one thing that is very good about India is that the family structure is so much inborn in us and in our culture that though being MSM, if people are working in a CBO, it's like a family. Everybody is available for everybody, it's like that. Of course we have differences for each other, politically we have differences, but

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when it comes to support each other, of course we all come as a community in a very strong way.

So MSM CBOs have really built up in supporting people living with HIV/AIDS when they are in community care centers or at their houses, because I have seen through my own 10 years of experience how nobody was left alone till the last date or till the last breath. How everybody was intact.

When there were no services, we fought for services together. At platforms where sexual minority was discussed, we fought for our own spaces. But when it was to access services we were together. So that was MSM sector.

Let me take you to India. India itself as a continent as we all know. So big. And we are such political people. We fight, fight, fight. Yeah, it's strange. So transgenders, I started way back in 1999 saying that to the government, we are not men. We are transgenders. Then suddenly some effeminate men stood up and said, we are transgenders. So I said "Oh my God, then, my community has again gone to one side!" Then we said "Okay, you have your space of transgender. We are Indian hijras."

Now hijra in itself is a community altogether. It is a culture; it has been century down the lines in our continent, and it's the only sexual minority which is visible in our side, which is not only India Pakistan Bangladesh and the Terai region of Nepal. So this community is there. Like for example my guru is my (inaudible

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00:49:47). Father, mother, everything. If she dies, I inherit all her property. And then my disciples are my children. The disciple and like my guru has 15 other disciples, and I am among 15, but whoever takes the care, till her last breath, deserves her property. That goes by saying and it's like everything is with the community. But there was a position in our side that there are so much of myths and misconcepts, India being with so much of religion, religious gurus, and all the stuff.

Hijra in itself is a religion. We follow both Islam and Hinduism very strongly. It has not been changed form after the Britishers – what Britishers did to our community also, until now we have not come out of it. Lack of education systems – so still we follow the old and the ethnic norms in our community.

When we started our work, it was really very hard. And there is so much of myths and misconcepts about us and our community in the mainstream society. When we did our first – in 2002, we did our first central surveilliance positivity rate was 49%. And I forced the government to do that, because I used to see people dying, doctors not touching them.

There was an incident where one hijra died at the door of a hospital. But I reached there, and she was dead. And we had lot of fight, because if at the right time, medicines were given to her, she would have been living till the date. But these incidents really

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gave a role to me to fight with the government and to access services which is there.

We have a beautiful, we have three drugs which we get enroll [misspelled?] but over there was a problem that – how to touch a hijra, health care providers. So it took us a long time in educating, and accessing services what was there for us.

And once I remember I took five patients for the ART drugs, and the main doctor, you know, he became mad. And he used abusive language. In a big hospital, government hospital. On the first floor was the cabin. I dragged him by the collar and pulled him down on the streets, you know? I hammered him. I'm a nasty activist, you know?

But then afterwards the press took it seriously, and one thing was very good: that the press supported us. And after that incident, everybody – out of fear, but still, we got access. Anyway, we should receive access for the community.

And then they were a few very big cases where very rich gurus were there and they have lots of money with them. Because we have money from – it's hierarchy. After me, my disciples will get – and all the money is with the community. So they're rich. They can afford. But they don't know how to tackle HIV and AIDS.

So when we start at first it was like, "Oh, we don't have sex." Because hijras are not supposed to have sex because they are

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godly people. People are scared of their curse and believe in their blessing in our country.

So when we asked for the project from the government, and they said you don't have sex – well, excuse me, I'm as human as you. It's my basic necessity to have sex. You know? So it started with that. Because we broke the ice and we got into it.

Like two, three hospitals were really very trans-phobic and hijra-phobic. But we could achieve. I used my femininity sometimes. My strapless blouses made the good way to enter the man's world. You know, my saris used to just slip down. And it was okay for the Indian man to pay more attention for us. But we did every method to get medicines, to get support.

Now one rule is there in the community care center. If you put somebody, you require somebody for 24 hours, a family member, to be there. That was not a big deal with us. For example, at the dawn of this conference, it's sad that I lost my disciple.

I crossed the security and the immigrations of India, and I got the news that my disciple expired. Her name was Payan [misspelled?] and she was a wonderful cook. I will miss back home.

We never knew she was positive; in four days everything happened. She became hepatitis positive and she was HIV positive. Her kidneys failed. We could not save her.

But 24 hours, there was a shift always within the family of our hijras that, people would go and take care. At present, our

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organization doesn't have government funds. But we have our own system to access funds when it is required for people who are positive, people who cannot [Applause] – because this disciple of mine was very near to me. I saw to it she was given the best medical facilities.

One thing is good about India, that we transgenders and we hijras are totally "out." There is nothing but there is stigma, visibility always gives stigma. If you are positive it doubles the stigma.

One thing I'm really proud what we have in our country, and the hijra community especially, is the family bond between each other. And I believe that this is a good nature, where the world should learn, that immaterial to anything, we are one and we should stand by each other immaterial to our sexuality, our gender identity, or our age. Youth, child, young, old. Because HIV doesn't discriminate, so we shouldn't discriminate. Thank you. [Applause]

JOHN MILLER: Thank you very much. I'm going to turn it over to my co-chair, Stefan.

STEFAN GERMANN: Thank you so much. Before we go into opening up for the floor to just sort of recap a couple of things, I think that what came out really strongly in this session is the importance of looking at the history of the AIDS response, which has focused predominantly in most areas on individuals.

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So for a long time, the unit of analysis of our work, of our learnings, of our plannings, of our intervention was mostly around individuals. But kind of the whole truth of the importance of families and that sort of network, clearly we need to shift. And I think we have seen over the last couple of years a gradual shift, increasingly to focus the unit of analysis into families. And then we've heard from the Eastern European regions who see that it takes time to shift. And I talked with Marine shortly before the presentation, and she said it's good to see and hear as well in this conference that the families are much more mentioned. I was very pleased for example that Paul DeLay, in most of his addresses, he always ends with the importance of fathers, families, and sort of bringing that concept in.

The challenge though is really to shift from language to practice. And that is sort of the journey we have to go together over the next couple of years. Elaine gave us a very in depth – and I really appreciated the slide looking at that continuum, in terms of family-centered interventions.

And integration will increasingly be a very key theme. As we've heard as well in this conference, the UN Secretary General just launched a draft of a joint action plan for women's and children's health, and this is an opportunity to really bring up, this morning Elaine had that sort of picture

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of the house, and I think that some of us from the coalition of Children Affected by AIDS would like to work with you on that picture, which is a good start. But I think there is more to it than these two houses bringing under one roof. So we can work together on that.

Then thank you Maurice: I think you brought up some real issues in terms of legislative challenges. Few of us actually look at the legislative pieces going back into 1860, but we see that if we start to talk family-centered approaches we don't have to be naïve in the sense of, within our immediate environment. We have to look at the whole legislative framework and what does it mean specifically to marginalized communities.

And Laxmi, thank you for bringing that hirja, the family bond and what I've picked is, we are one, and should stand to each other. And it is this oneness, the concept of family, across the various communities. Thank you.

JOHN MILLER: It's very warm in here. I see my colleague from Jamaica fanning himself. They're not as used to the heat as we are in Canada. [Laughter] We have some time for questions, though. So please feel free to come to the microphone, introduce yourself and tell us where you're from, and ask questions of the panelists or add your own experiences around family-centered support.

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FEMALE SPEAKER: Thank you. Thank you for an excellent panel. I have a question, which is open to the whole panel. One of the things that strikes me consistently about family based approaches is that they cost more because they are – they are paid to cost more because they are addressing the entire family rather than an individual approach.

However, your evidence seems to suggest the eventual cost benefit could be greater. And I wonder if there was any scope if or if there has been any costing analysis done, which could be used to help promote family center care?

ELAINE ABRAMS: I can say, not that I know of. MT50Plus was a demonstration project, so it was learning as it went along. So, there wasn't any cost analysis. As I said, there've been so few exact models that I don't think it's been done. But I honestly don't know.

STEFAN GERMANN: Just two things on that question. UNFPA did a series of case studies and they started to look at some of the element of costing. But it's clearly important that we invest in actually look into that costing. But I think Professor Linda Reichert [misspelled?] she made a very important point relating to the costing. It's you have to look at both sides of the equation.

Cost to who? Is it more costly to the service provider? But what about the cost of a woman that has to go first to get

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her family planning here, and the ARVs over there. Then if she has a child she has to go to the other end of town. So the transport cost, the time cost, the emotional cost of not having that integration is a significant cost. If we do costing analysis, let's look on both sides of the equation.

MARINE ADAMYAN: A quick response. The Uzbekistan I mentioned for the family center approach we introduced into the program. Later on, it didn't cost us anything simply because we were bringing dependants to the same counseling that we were inviting the drug users to come in the trust point.

And at the same time, we were doing all the other interventions because it was a comprehensive program, like; we were addressing them in the shooting galleries. And their peers were doing it. It's not that the program staff was doing it. So it was very much a peer approach, but also professional counseling to dependents and family members. It didn't cost us anything. Zero additional dollars was spent, basically, but it really added huge value to the program and it benefited the program a lot.

MARINE HORNAY: Hello. My name is Marine Hornay [misspelled?] from Repsi [misspelled?] as well as Reiat, [misspelled?] eastern southern Africa.

I have comments. My first comment is good to hear the different types of families presenting on strengthening

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families. I think that a positive adaptation to the where this conference is going. I would love to hear a little bit more about households that are being headed by children.

And then secondly, my question is does any one of you have experience or information about what could be the psychological affects, of the different types of families, that you are presenting? Thank you.

MAURICE TOMLINSON: I think your first point is very excellent. The [inaudible] that is – two of the children that we eventually took into our care, through Jamaica AIDS Support for Life, were heading households where both of their parents had died. And they were just happened upon by chance. It really would be important to identify what is the level of care they were able to provide for their other siblings, who were also infected. It was a very excellent question.

In relation to your second question I believe in – that's my new mantra, heart of it and so for and hysterical emotion. And I know that, in all, society in Jamaica there a tendency to think that it's a non-normal situation and the children must be hurt; they must be harmed by that situation. Yet the longitudinal studies are being weighed on, in the United States, by the American Psychological Association, is informing us that the children are performing quite well in the non-normative context.

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And so for me that kind of research is simply exciting. We just have to rely on all the studies that are being done elsewhere in the world. But certainly what going on right now is that the children are performing – all their indicators are quite good.

STEFAN GERMANN: On the child head of household question, I published a study in 2005, focusing on coping capacities and quality of life, childhood households, in Europe and Southern Africa, and what came out very clearly in that study was that actually mobilized communities, and community support and neighborhood support, child headed households reconstitute themselves into these family clusters within the neighborhood.

And we identified that there are situations social welfare or social workers interfered, and sort of broke up these family concepts that it was detrimental to the children by breaking them up. Whereas within a neighborhood supported child head of household concept, the family unit was carrying on and functioning well.

LAXMI TRIPATHI: I would like to add upon the second question, too. That as I told you the guru – in our community we have gurus and we decide the heads of the community, who decide what is good and bad for the community so when we started condom giving, they said we are not into sex. And only

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the community who is to – the part is, we have three professions. One is to blessing, one is to begging, and one is to sex work.

Only the sex worker is to take condoms. But then people started dying, due to HIV/AIDS. The whole shift changed then; emotionally scattered and then they realized, then it took us time not to poke their nose into any of the health issues of the community.

It brought more strength together to the community, to be together, and to be one. Because I remember an incident, where one of the gurus threw a disciple out of the house because she was positive; but the head of the community took a decision to find the guru, and to pay for all of her health services to be provided in a private center. So that brought oneness together back to the community, which was losing of it.

CRYSTAL OWER: Hello. My name is Crystal Ower [misspelled?] I'm with the Global Forum on MSM and HIV. I'd like to really applaud this panel. I thought it was very well done, and I'm especially appreciative the panelist who provided some insight into families, that don't necessarily adhere to hetronormative assumptions, of what makes up a family unit. So I thank you very much.

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And, to that affect I was wondering if the panel could speak a little bit more about creating, and enabling environments for these families, to access family-based care.

Certainly there is an excellent analysis of some the of structural and legal dimensions, but barriers that need to be addressed. But beyond legal reform, are there any strategies that can help create this enabling environment, for broader access? Thank you.

LAXMI TRIPATHI: A based, community organization. A community based organization should be strengthened, because that is an example which I have seen, which blaze in a very strong way. Because when communities are given the power to take up the compressive projects, then the oneness and family being becomes stronger, and the approach becomes much more. It's an authentic approach to that community, which is not such a heterosexual community.

We are not heterosexual, not MSM. But one thing we have seen we're coming together and having the power in our hand, and we know that sometimes people have power, but don't know how to act. Give out and there are good, noble projects across the world, which should be taken into consideration and make it happen across the world.

JOHN MILLER:I just wanted to also comment that a number of us have been having discussions at this conference about the

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need to address the very real issues that staff, workers in eight service organizations and health care organizations in hospitals, and there are other kinds of health care workers, and social service workers are having in providing services to the especially marginalized populations, in a family centered way.

And that there is a real need for other standards or a set of guidelines, guiding principles to break down stigma, but also to allow those workers to deal with some very real issues that are emerging because of legal frameworks, in various countries; where rights can collide. So where they may have duty to report sexual abuse, for instance, and how that might impact on inadvertent disclosure of someone's HIV status, when they do that.

The issues of the MSM in particular and sex workers and IDUs, bring these issues to the fore, especially when people carry with them all sorts of discriminatory notions. And it's very hard for workers to pick them apart, and I think we've been burying our heads in the sand about addressing these issues, so that the barriers are broken down.

MAURICE TOMLINSON: If I could make just one, final quick comment on this one, anyway. This situation in Jamaica recently occurred where the Minister of Education had withdrawn a book from the syllabus, which had been approved by his own

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ministry, talking about families. And in that book there was a reference a non-normative families, as being families, or a form of families.

There's definitely been an attempt to mis-educate Jamaican students about the existence of these kinds of families. The reason this is allowed is because of the law. The law which criminalizes same sex intimacy.

So even though the facts are such families exist, you can deny their existence on a policy level because the law says they shouldn't exist. So, you have to start with the law.

JANETTE ALOTTA: I am Janette Alotta, from World Vision Canada. I would like the panel to talk about changes, like in the social, cultural factors around in families; the roll of the families in vertical transmission. That always is so positive. We've done research, like if there were factors that were an obstacle for women to continue in their care, and the position of grandmothers, mothers-in-law, husbands and extended family. There can sometimes be a challenge for the service.

ELAINE ABRAMS: I think you're talking about a number of different things, though those are not really challenges, to family focus care. Many of those things have been identified as challenges, to PMTCT; and that I think is somewhat different. I think the major challenge to family focus care is getting buy-ins to actually try and do that. But I can speak to the

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experience of the PMTCT Plus Initiative, where we thought by empowering women, to bring in their families that would be the end; and of course, they'd bring in their families, and that really turned out not to be the case.

As you saw from partner in Roman, that many women didn't want to disclose to their partners; many women lived in discouraged partnerships, many women had children had children living outside of their homes, with grandmothers and such. So, to the actual details of providing family focused care turn out to be quite complex and have to be really fine tuned to the particular environment.

And many of these barriers of things that have been talked about for the last four days around stigma, gender inequity, educational level and marginalized populations.

JOHN MILLER: Also, we had a presentation on the collation on children affected by AIDS to some meeting especially marginalized populations, in February, by Dr. Catchier Burns, where she highlighted that yes, sometimes families in and of themselves, would be a liability; they're not always supportive and loving, particularly with drug using mothers. And that there is a lot of – we have to remain and I think Dr. Adamyan has been pointing out some of those challenges.

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STEFAN GERMANN: Well, I would like to sort of make a note that you get out, please take a copy of the Journal of the International AIDS Society, where together with the International AIDS Society, the Collation of Children Affected by AIDS and the joint learning imitative fund children and aids, put together a collection of evidence based articles. The publication is called Family Centered Services for Children Affected by HIV and AIDS. It's a very useful publication. And so please when you get out take some of these on the table there.

MARK ATWELLER: My name is Mark Atweller, I'm with Hope Worldwide, and I guess one concern is that we've talked about the rights of almost everyone here, except for the 16 Million orphans and vulnerable children in Africa.

And my question is simply in your organizations, how do you envision extending the family approach to those orphans and vulnerable children.

MAURICE TOMLINSON: Well, for me the option would be to all the family types to be recognized. I mean, that's what we're advocating in Jamaica; allowing other non-normative families to get the benefits, to take care of these vulnerable children.

But the hassle, especially in my context, of taking in such a child just dissuade. For example, an MSM or a Lesbian

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couple, doing that, and I'm speaking from the Caribbean perspective. I don't know what the percentage or availability of that is in Africa.

STEFAN GERMANN: In terms of the question specifically I think even if there are more, as well to Africa, I think there's two key elements. I think one is, in short, that we keep mothers alive, and keep the children with their parents, so that in terms of the situation of treatment is very important because you were referring to mother and children.

Secondly, children have a right to family. That's is the right within the CRC. And if you look at the large numbers of orphans and vulnerable children, they do tend to have some form of form of family networks. But quite often issues related to family unification. Issues, coming out of the study on child-headed households, the key factors, the key determining factor where the child of head of households existed, was actually family conflict before the onset of HIV.

And so issues around family support is so critical. In the Children's Aid Pre-Conference, we had an interesting study presented from China, which was looking at the psychological and psycho-social outcomes of children within kinship families, so the family home is an institution.

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And the results showed that against our experience in Africa is that children within the family sort of home were better off than children in the kinship home.

However, when we then asked to the presenter, we quickly found out that the government was supporting the, the home arrangement, but the government was not supporting at all to kinship families. Now you compare strawberries with peaches. Whereas, if you this the same resources into supporting families and kinship networks, to take care of the children; and then have the social protection networks. And I think for Africa that is the most important aspect for orphans and vulnerable children and families is social protection which give the economic basis for families to cope.

JOHN MILLER: Are there any other questions? If no, then I'd like to thank all of our panelists for a very interesting presentation, and say thank you for coming.

[Applause]

[END RECORDING]

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